

ETHICAL PRACTICES IN END-OF-LIFE CARE

About this Module

This module is designed to introduce basic concepts and identify common misconceptions about ethical aspects of end-of-life care. It is intended to stimulate discussion and reflection rather than to present comprehensive knowledge in the subject area.

After learning about the ethical aspects of end-of-life care through **Definitions, Your Responsibility, and Foundations**, you will be presented with a series of **Case Studies** that illustrate scenarios in which a staff person is faced with a situation that raises an ethical concern. Each case study ends with a decision that needs to be made and a choice of four options. After you choose the option you think is most appropriate, review the feedback provided at the end of this document that explains the ethical aspects that inform the decision. At any time, you can go back to review the **Definitions, Your Responsibility, and Foundations** provided below.

After working through all the cases, please review the summary of **Key Points**, resources for finding out **More Information**, and suggestions for further **Discussion** with colleagues.

This module is part of a larger VHA initiative, IntegratedEthics®, which aims to help facilities create effective health care ethics programs to improve ethics quality nationwide.

Definitions

Term	Definition
Goals of care	Objectives identified through shared decision making that can be guides for treatment. Examples include cure, maintaining function, prolonging life, improving quality of life, relieving suffering, relieving pain, a dignified death. Goals of care should be discussed with a focus on what outcomes are achievable (i.e., dictated by the patient’s prognosis) and what is desired by the patient.
Palliative care	Palliative care is an approach to life-threatening chronic illnesses and care near the end of life that combines active and compassionate therapies to comfort and support patients and their families. Palliative care strives to meet physical needs through pain and symptom relief and maintaining quality of life while emphasizing the patient’s and family’s rights to participate in informed discussion and to make choices. This patient- and family-centered approach uses the skills of interdisciplinary team members to provide a comprehensive continuum of care that includes attention to physical, spiritual, and emotional needs. The principles of palliative care can be applied throughout the disease course, even when death is not near and/or when the goals of care are to maximize length of survival.
Self-determination	The right of individuals to make decisions for themselves and to have decisions made in accordance with their preferences and values even after they have lost capacity to make decisions themselves.
Shared decision making	The process of collaboration between clinician and patient in making health care decisions, to which the clinician contributes his or her expert knowledge and compassion, and the patient his or her values, preferences, and goals for care.

Your Responsibility

In cases of advanced illness, when the patient’s prognosis may be uncertain or very poor, patients and clinicians must make difficult treatment decisions, for example about artificially administered nutrition and hydration or levels of pain control and sedation. Sometimes a patient or surrogate asks to withdraw life-sustaining treatment — or the reverse, requests care that the health care team believes to be excessively burdensome or futile. Clinical and administrative staff are responsible for assuring high quality care by:

- assuring that the goals of care are appropriately identified and revised as needed through a process of shared decision making
- respecting the patient’s right to determine the goals for his or her care

- offering the patient effective palliative care
- continuing to actively care for the patient even when cure or prolonged survival are no longer goals
- developing and implementing systems and processes to promote ethical practice in end-of-life care

The cases in this module sometimes reflect the decisions made by a particular member of the health care team, but the principles are important for all.

Foundations

Historically, end-of-life care was shaped by a presumption in favor of curative medical interventions. Any decision not directed specifically at maximizing survival was understood negatively as "withdrawing," "withholding," or "refusing" treatment. With the evolution of hospice and palliative care, care-giving goals of comfort, relief of suffering, and a dignified death have come to be recognized as positive and appropriate for patients with advanced illness. To honor the range of end-of-life options available to patients, palliative care emphasizes shared decision making that is based on explicitly identifying achievable and desired goals of care.

Your responsibility to provide respectful and clinically appropriate care at the end of life is based on four ethical obligations:

1. **Your obligation to respect the patient's right to self determination.**
This right, sometimes referred to as autonomy, is well established in law and ethics, and best summarized in the words of Justice Benjamin Cardozo in the 1914 court case that gave legal recognition to the concept of informed consent: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."
2. **Your obligation to prevent or remove harm and to promote the patient's good.**
This is also known as beneficence.
3. **Your obligation to refrain from causing harm or imposing unnecessary risk.**
This is also known as nonmaleficence.
4. **Your obligation to not abandon the patient.**
The healing relationship is distinguished by the vulnerability of the patient, the imbalance of knowledge and power between the health care provider and patient, and the expectation that health care providers will use their knowledge and skill to help the patient. Patients have a legitimate expectation that their welfare will be paramount and that they will not be abandoned by their health care providers.

These ethical obligations are the basis for legal precedent and VHA policies on ethical practices with respect to end-of-life care.

Case Study 1

Ms. Steinberger has multi–system organ failure and massive intestinal necrosis (dead gut). She is expected to die despite aggressive therapy.

As the spokesperson for the interdisciplinary team caring for Ms. Steinberger, what should you discuss **first** when you talk with the patient?

- A. Explain Do-Not-Resuscitate (DNR) orders.
- B. Recommend a palliative care treatment plan.
- C. Explain the various treatment options.
- D. Clarify the goals of care.

(See end of document for feedback.)

Case Study 2

Mr. Santos has end–stage Alzheimer’s disease that has left him bed bound and unable to interact. Mrs. Santos, the patient’s wife and authorized surrogate, has discussed treatment goals with the health care team, and all are agreed on a plan for comfort care only.

How should the physician handle DNR orders?

- A. The physician should write a DNR order.
- B. The physician should notify Mrs. Santos that he is going to write a DNR order, and make sure she does not object.
- C. The physician should explain to Mrs. Santos what is meant by a DNR order, recommend a DNR order as the best way to achieve the goal of comfort care, and make sure she does not object.
- D. Discuss the risk and benefits of CPR and ask Mrs. Santos if she wants her husband to be resuscitated in the event of cardiac arrest.

(See end of document for feedback.)

Case Study 3

Mr. Small is an 84–year–old WWII Veteran who lacks decision–making capacity due to multiple strokes. After a brief hospitalization, he is admitted to a long–term care facility

where you are his nurse. The nursing student assigned to you asks, "I noticed Mr. Small has an advance directive. Should we ask the doctor to write a DNR order?"

What should you do?

- A. Make sure the doctor is aware that the patient has an advance directive.
- B. Read the advance directive and determine whether it applies in the patient's current clinical circumstances.
- C. Explain to the student that she shouldn't assume Mr. Small wants to forgo cardiopulmonary resuscitation just because he has an advance directive.
- D. All of the above.

(See end of document for feedback.)

Case Study 4

Mr. Shapiro completed an advance directive consisting of a living will, in which he specified his preferences regarding certain life-sustaining treatments. Although he has several close relatives, he did not designate a health care agent to make decisions on his behalf. He has multiple medical problems, including COPD, currently lacks decision making capacity, and his respiratory status is tenuous. Imagine you had to decide whether to begin mechanical ventilation, if it should become necessary.

What should you do **first**?

- A. Write orders to carry out the patient's wishes as expressed in the advance directive.
- B. Read the directive to determine whether it applies under the current circumstances and if so, what the patient would want, then write orders to carry out the patient's wishes.
- C. Identify a surrogate and ask that person what should be done for the patient.
- D. Identify a surrogate, review the advance directive with the surrogate, and collaborate with the surrogate to arrive at treatment decisions that are consistent with the patient's wishes as articulated in the directive.

(See end of document for feedback.)

Case Study 5

Mr. Stern has Parkinson's disease and has diabetes. One week ago he suffered a serious stroke, and as a result he cannot swallow safely. An NG tube (which goes through the patient's nose into his stomach) is in place for the administration of medication. The GI (gastroenterology) consult recommends beginning tube feedings.

If you had to make a decision in this case what would you do?

- A. Begin artificial nutrition and hydration through the NG tube.
- B. Explain to Mr. Stern that you need to convert the NG tube to a percutaneous endoscopic gastrostomy (PEG) tube (which goes through an incision in the patient's abdomen into his stomach and small bowel) so that nutrition and hydration can be artificially administered on a long-term basis.
- C. Ask Mr. Stern whether or not he would like to receive artificially administered nutrition and hydration.
- D. Explore with Mr. Stern his goals of care and discuss whether or not artificially administered nutrition and hydration seem right for him.

(See end of document for feedback.)

Case Study 6

Ms. Sheppard is 46 years old and has breast cancer metastatic to the bone and liver. She doesn't want the nurses to change her bed sheets because it worsens her pain when they move her. Ms. Sheppard is already on a very high dosage of morphine, and her physician is concerned that higher doses may cause her unwanted side effects, or even hasten her death.

What should the interdisciplinary team caring for Ms. Sheppard do?

- A. Change Ms. Sheppard's sheets only if necessary.
- B. Give an extra dose of morphine before each bed change.
- C. Increase the dose of morphine until Ms. Sheppard no longer experiences any pain.
- D. Discuss pain management options with Ms. Sheppard and manage her pain in accordance with her wishes.

(See end of document for feedback.)

Case Study 7

Mr. Allen is a 73-year-old Korean War Veteran with a history of squamous cell carcinoma of the lung and COPD who has been admitted for shortness of breath. He has an advance directive and a DNR order. You're at the nursing station and the nurse's aide tells you that Mr. Allen has just reported that his shortness of breath is much worse. His blood gas results indicate impending respiratory failure.

What should you do?

- A. Order 5–10 mg of IV morphine as needed for shortness of breath, and call his family.
- B. Call respiratory therapy STAT, and arrange transport to the ICU.
- C. Send a respiratory therapist and a nurse to his bedside while you check his advance directive.
- D. Go see him and discuss the options.

(See end of document for feedback.)

Case Study 8

Mr. Fiebach is an 83-year-old man with end-stage liver failure. He is confined to bed and needs assistance with all of his activities of daily living. His wife asks about the possibility of hospice care.

How do you respond?

- A. Tell her that since his prognosis cannot be predicted with certainty, he is not a candidate for hospice.
- B. Offer to transfer him to an inpatient hospice bed when one becomes available.
- C. Offer to arrange home care with a hospice provider in the community.
- D. Determine whether he meets the eligibility criteria for hospice care.

(See end of document for feedback.)

Case Study 9

Stanley Shield is a 53-year-old Vietnam Veteran with a three-year history of amyotrophic lateral sclerosis (Lou Gehrig's disease). He had been cared for at home by his wife until recently, when he began to experience shortness of breath. He had

decided against mechanical ventilation, and is expected to die soon of respiratory failure. You and your team have just finished reviewing his case outside his door on morning rounds.

What should you do next?

- A. Don't burden him with routine visits; move on to the next patient.
- B. Assign one person from the team to come back and visit Mr. Shield later.
- C. Knock on the door, pause a moment, then enter as a team, as you would with any other patient.
- D. Check with his primary nurse to make sure his symptoms are adequately controlled.

(See end of document for feedback.)

Case Study 10

Mrs. Rubin is a 72-year-old Veteran who was given cardiopulmonary resuscitation (CPR) after a cardiac arrest. In the six months since, she never regained consciousness and is now in a persistent vegetative state (PVS). Mrs. Rubin has an advance directive that states she would not want any life-sustaining treatment, including a feeding tube, if she were ever in PVS. Her advance directive also names her husband as her health care agent. As the physician caring for Mrs. Rubin, you want to honor her advance directive and discontinue life-sustaining treatment, but Mr. Rubin is not willing to withdraw the feeding tube despite several family meetings.

What should you do?

- A. Withdraw the feeding tube on the basis of the advance directive despite Mr. Rubin's objections.
- B. Continue to give Mrs. Rubin artificial nutrition and hydration through the feeding tube.
- C. Seek an ethics consultation.
- D. Seek a court order to withdraw treatment.

(See end of document for feedback.)

Key Points

End-of-life care is concerned with decisions about care for patients nearing the end of their lives. A crucial role for all clinicians, whether physicians, nurses, social workers, chaplains, physical therapists, or nurse's aides is to help patients and families make decisions that are often difficult. Clinicians should provide information and advice while respecting the patient's preferences and goals of care. The ethical aspects of end-of-life care include decisions about life-sustaining treatments (such as cardiopulmonary resuscitation or artificially administered nutrition and hydration), futility, treatments that hasten death, etc.

Summary of key points:

1. Clarify the goals of care before making decisions about end-of-life care.
2. Make recommendations consistent with goals.
3. Don't assume that a patient who has an advance directive does not want CPR.
4. Rely on the surrogate to help interpret the patient's advance directive.
5. Give the patient or surrogate the opportunity to accept or refuse all life-sustaining treatments, including artificially administered nutrition and hydration, which are consistent with desired and achievable outcomes and goals.
6. Provided they are consistent with the patient's goals of care, comfort measures and pain management should always be a priority, even if they may shorten life.
7. Unless other treatment limitations have been agreed on, treat patients with DNR orders as you would other patients except if they experience cardiopulmonary arrest.
8. Hospice is a philosophy and approach to care, not a place.
9. Resist the temptation to avoid patients who are dying.
10. When you cannot resolve situations of uncertainty or conflict regarding end-of-life care, seek an ethics consultation.

More Information

For more information or if you have questions or comments regarding the IntegratedEthics® initiative, please contact:

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Discussion 1

Now that you understand some of the basic concepts and common misconceptions about ethical aspects of end-of-life care, consider this case:

Mr. Kroog, a Korean War Veteran, decides to discontinue dialysis and is expected to die within a few weeks due to renal failure. In the meantime, he wishes to be resuscitated in case of cardiac arrest. The health care team is uncomfortable with the prospect of resuscitating a patient who has decided to forgo all other life-sustaining treatments.

Discuss this case with your colleagues:

- What values, beliefs, or principles are in conflict in this case?
- What should the health care team do to resolve the conflict?

Discussion 2

In many respects, end-of-life care requires both ethics knowledge and communication skills that improve with practice. One key skill in maintaining a trusting therapeutic relationship is communicating honestly about prognosis without diminishing hope. This situation often arises when a patient asks "how much time do I have left?" There are many ways to respond to such questions; an effective approach must be tailored to the particular clinical situation. To respond to this question appropriately, it is important to understand the patient's motivation. All patients seek reassurance — for some, factual information about their likely prognosis will offer a sense of control; others may be more comfortable with a more open-ended description of their future. Possible approaches include asking:

- *"Boy, that's a hard question. Let me start by asking you, what is your current understanding of your situation?"*

- *"Are you looking for specific numbers, or should we talk more generally about what might happen?"*
- *"There are a lot of ways to talk about prognosis — what sort of information would be most useful to you?"*

Get together with colleagues and share ideas for how you can discuss prognosis and treatment options for patients near the end of life.

Case Study Feedback

Case Study 1

The correct answer is: D. Clarify the goals of care.

A. Explain DNR orders.

This isn't the best place to start. Before discussing any specific treatment plans or options, it is important to first clarify the goals of care and how they should be prioritized. Goals of care and treatment priorities often change as patients approach the end of their lives. As prognosis worsens, the goals of prevention, cure, or avoidance of death may become less important, while relieving suffering and optimizing quality of life may become the primary goals. Because these conversations require specific skills, clinicians must be appropriately trained to discuss goals of care sensitively and effectively. Once the goals of care are clarified, a care plan can be discussed and collaboratively designed with the patient and family.

B. Recommend a palliative care treatment plan.

This isn't the best place to start. Before discussing any specific treatment plans or options, it is important to first clarify the goals of care and how they should be prioritized. Goals of care and treatment priorities often change as patients approach the end of their lives. As prognosis worsens, the goals of prevention, cure, or avoidance of death may become less important, while relieving suffering and optimizing quality of life may become the primary goals. Because these conversations require specific skills, clinicians must be appropriately trained to discuss goals of care sensitively and effectively. Once the goals of care are clarified, a care plan can be discussed and collaboratively designed with the patient and family.

C. Explain the various treatment options.

This isn't the best place to start. Before discussing any specific treatment plans or options, it is important to first clarify the goals of care and how they should be prioritized. Goals of care and treatment priorities often change as patients approach the end of their lives. As prognosis worsens, the goals of prevention, cure, or avoidance of death may become less important, while relieving suffering and optimizing quality of life may become the primary goals. Because these conversations require specific skills, clinicians must be appropriately trained to discuss goals of care sensitively and effectively. Once the goals of care are clarified, a care plan can be discussed and collaboratively designed with the patient and family.

D. Clarify the goals of care.

Good choice. Before discussing any specific treatment plans or options, it is important to first clarify the goals of care and how they should be prioritized.

Goals of care and treatment priorities often change as patients approach the end of their lives. As prognosis worsens, the goals of prevention, cure, or avoidance of death may become less important, while relieving suffering and optimizing quality of life may become the primary goals. Because these conversations require specific skills, clinicians must be appropriately trained to discuss goals of care sensitively and effectively. Once the goals of care are clarified, a care plan can be discussed and collaboratively designed with the patient and family.

The bottom line: **Clarify the goals of care before making decisions about end-of-life care.**

Case Study 2

The correct answer is: C. The physician should explain to Mrs. Santos what is meant by a DNR order, recommend a DNR order as the best way to achieve the goal of comfort care, and make sure she does not object.

A. The physician should write a DNR order.

This isn't the best option. Once the patient (or surrogate) and the health care team have agreed on goals of care, it's not necessary to discuss in detail the risks and benefits of any treatments that are not consistent with those goals. Nonetheless, it is important that the patient or surrogate be informed about orders that affect the patient's care. Instead of presenting all options, however, you should make a specific recommendation about how best to achieve the agreed on goals. In this case, the physician should explain to Mrs. Santos what is meant by a DNR order, recommend a DNR order as the best way to achieve the goal of comfort care, and make sure she does not object. If Mrs. Santos disagrees with the recommendation, the physician should explore further the inconsistency between a goal of "comfort only" and the specific treatment request, including addressing her emotions about withholding medical treatment.

B. The physician should notify Mrs. Santos that he is going to write a DNR order, and make sure she does not object.

This isn't the best option. Once the patient (or surrogate) and the health care team have agreed on goals of care, it's not necessary to discuss in detail the risks and benefits of any treatments that are not consistent with those goals. Nonetheless, it is important that the patient or surrogate be informed about orders that affect the patient's care. Instead of presenting all options, however, you should make a specific recommendation about how best to achieve the agreed on goals. In this case, the physician should explain to Mrs. Santos what is meant by a DNR order, recommend a DNR order as the best way to achieve the goal of comfort care, and make sure she does not object. If Mrs. Santos disagrees with the recommendation, the physician should explore further the inconsistency between a goal of "comfort only" and the specific treatment request, including addressing her emotions about withholding medical treatment.

C. The physician should explain to Mrs. Santos what is meant by a DNR order, recommend a DNR order as the best way to achieve the goal of comfort care, and make sure she does not object.

Good choice. Once the patient (or surrogate) and the health care team have agreed on goals of care, it's not necessary to discuss in detail the risks and benefits of any treatments that are not consistent with those goals. Nonetheless, it is important that the patient or surrogate be informed about orders that affect the patient's care. Instead of presenting all options, however, you should make a specific recommendation about how best to achieve the agreed on goals. If Mrs. Santos disagrees with the recommendation, the physician should explore further the inconsistency between a goal of "comfort only" and the specific treatment request, including addressing her emotions about withholding medical treatment.

D. Discuss the risk and benefits of CPR and ask Mrs. Santos if she wants her husband to be resuscitated in the event of cardiac arrest.

This isn't the best option. Once the patient (or surrogate) and the health care team have agreed on goals of care, it's not necessary to discuss in detail the risks and benefits of any treatments that are not consistent with those goals. Nonetheless, it is important that the patient or surrogate be informed about orders that affect the patient's care. Instead of presenting all options, however, you should make a specific recommendation about how best to achieve the agreed on goals. In this case, the physician should explain to Mrs. Santos what is meant by a DNR order, recommend a DNR order as the best way to achieve the goal of comfort care, and make sure she does not object. If Mrs. Santos disagrees with the recommendation, the physician should explore further the inconsistency between a goal of "comfort only" and the specific treatment request, including addressing her emotions about withholding medical treatment.

The bottom line: **Make recommendations consistent with goals.**

Case Study 3

The correct answer is: D. All of the above.

A. Make sure the doctor is aware that the patient has an advance directive.

Yes, but making sure the doctor is aware of the patient's advance directive isn't enough. This case suggests a gap in quality, ethics quality. Your facility should have a system in place to ensure that every advance directive is routinely reviewed by the clinician responsible for the patient's care. An advance directive is a complex document that requires interpretation before it can be acted upon. For example, every advance directive gives specific conditions that must be met before it takes effect, such as "if I have a terminal condition and death is imminent." In contrast, DNR is an order that takes effect as soon as it is written. In this case, the correct response is "all of the above."

B. Read the advance directive and determine whether it applies in the patient's current clinical circumstances.

Yes, but you should also address the student's misunderstanding about advance directives. This case suggests a gap in quality, ethics quality. Your facility should have a system in place to ensure that every advance directive is routinely reviewed by the clinician responsible for the patient's care. An advance directive is a complex document that requires interpretation before it can be acted upon. For example, every advance directive gives specific conditions that must be met before it takes effect, such as "if I have a terminal condition and death is imminent." In contrast, DNR is an order that takes effect as soon as it is written. In this case, the correct response is "all of the above."

C. Explain to the student that she shouldn't assume Mr. Small wants to forgo cardiopulmonary resuscitation just because he has an advance directive.

Yes, but there's even more to it. This case suggests a gap in quality, ethics quality. Your facility should have a system in place to ensure that every advance directive is routinely reviewed by the clinician responsible for the patient's care. An advance directive is a complex document that requires interpretation before it can be acted upon. For example, every advance directive gives specific conditions that must be met before it takes effect, such as "if I have a terminal condition and death is imminent." In contrast, DNR is an order that takes effect as soon as it is written. In this case, the correct response is "all of the above."

D. All of the above.

You're right. This case suggests a gap in quality, ethics quality. Your facility should have a system in place to ensure that every advance directive is routinely reviewed by the clinician responsible for the patient's care. An advance directive is a complex document that requires interpretation before it can be acted upon. For example, every advance directive gives specific conditions that must be met before it takes effect, such as "if I have a terminal condition and death is imminent." In contrast, DNR is an order that takes effect as soon as it is written.

The bottom line: **Don't assume that a patient who has an advance directive does not want CPR.**

Case Study 4

The correct answer is: D. Identify a surrogate, review the advance directive with the surrogate, and collaborate with the surrogate to arrive at treatment decisions that are consistent with the patient's wishes as articulated in the directive.

A. Write orders to carry out the patient's wishes as expressed in the advance directive.

This isn't the best option. The process of making decisions for patients who lack decision-making capacity is the same regardless of whether the patient has an advance directive or not. It should be a collaborative process between a person who acts as the patient's surrogate decision maker and the health care team. An advance directive is a statement of the patient's preferences, but a shared decision-making process is still required to decide how those preferences apply to the current circumstance. Therefore, you should never implement an advance directive without talking to the surrogate. In this case, since Mr. Shapiro has not designated a health care agent, you should first identify the authorized surrogate according to VA policy, then review the directive with the surrogate and educate him or her about the surrogate's responsibility to make decisions that are consistent with the patient's wishes as articulated in the advance directive.

B. Read the directive to determine whether it applies under the current circumstances and if so, what the patient would want, then write orders to carry out the patient's wishes.

This isn't the best option. The process of making decisions for patients who lack decision-making capacity is the same regardless of whether the patient has an advance directive or not. It should be a collaborative process between a person who acts as the patient's surrogate decision maker and the health care team. An advance directive is a statement of the patient's preferences, but a shared decision-making process is still required to decide how those preferences apply to the current circumstance. Therefore, you should never implement an advance directive without talking to the surrogate. In this case, since Mr. Shapiro has not designated a health care agent, you should first identify the authorized surrogate according to VA policy, then review the directive with the surrogate and educate him or her about the surrogate's responsibility to make decisions that are consistent with the patient's wishes as articulated in the advance directive.

C. Identify a surrogate and ask that person what should be done for the patient.

This isn't the best option. The process of making decisions for patients who lack decision-making capacity is the same regardless of whether the patient has an advance directive or not. It should be a collaborative process between a person who acts as the patient's surrogate decision maker and the health care team. An advance directive is a statement of the patient's preferences, but a shared decision-making process is still required to decide how those preferences apply to the current circumstance. Therefore, you should never implement an advance directive without talking to the surrogate. In this case, since Mr. Shapiro has not designated a health care agent, you should first identify the authorized surrogate according to VA policy, then review the directive with the surrogate and educate him or her about the surrogate's responsibility to make decisions that are consistent with the patient's wishes as articulated in the advance directive.

D. Identify a surrogate, review the advance directive with the surrogate, and collaborate with the surrogate to arrive at treatment decisions that are consistent with the patient's wishes as articulated in the directive.

Good choice. The process of making decisions for patients who lack decision-making capacity is the same regardless of whether the patient has an advance directive or not. It should be a collaborative process between a person who acts as the patient's surrogate decision maker and the health care team. An advance directive is a statement of the patient's preferences, but a shared decision-making process is still required to decide how those preferences apply to the current circumstance. Therefore, you should never implement an advance directive without talking to the surrogate. In this case, since Mr. Shapiro has not designated a health care agent, you should first identify the authorized surrogate according to VA policy, then review the directive with the surrogate and educate him or her about the surrogate's responsibility to make decisions that are consistent with the patient's wishes as articulated in the advance directive.

The bottom line: **Rely on the surrogate to help interpret the patient's advance directive.**

Case Study 5

The correct answer is: D. Explore with Mr. Stern his goals of care and discuss whether or not artificially administered nutrition and hydration seem right for him.

A. Begin artificial nutrition and hydration through the NG tube.

This isn't the best option. You shouldn't just assume that Mr. Stern wants to receive artificially administered nutrition and hydration. As with any other treatment, this is something that a patient (or the patient's surrogate) has a right to accept or refuse. It's necessary to obtain informed consent for the tube feedings. Ideally, the decision about tube feedings should be discussed within the context of a broader conversation about the overall goals of care. In this case, you should begin the discussion by asking Mr. Stern about his goals for care and whether or not he would like to receive this life-sustaining treatment.

B. Explain to Mr. Stern that you need to convert the NG tube to a percutaneous endoscopic gastrostomy (PEG) tube (which goes through an incision in the patient's abdomen into his stomach and small bowel) so that nutrition and hydration can be artificially administered on a long-term basis.

This isn't the best option. You shouldn't just assume that Mr. Stern wants to receive artificially administered nutrition and hydration. As with any other treatment, this is something that a patient (or the patient's surrogate) has a right to accept or refuse. It's necessary to obtain informed consent for the tube feedings. Ideally, the decision about tube feedings should be discussed within the context of a broader conversation about the overall goals of care. In this

case, you should begin the discussion by asking Mr. Stern about his goals for care and whether or not he would like to receive this life–sustaining treatment.

C. Ask Mr. Stern whether or not he would like to receive artificially administered nutrition and hydration.

This isn't the best option. It's good that you haven't just assumed that Mr. Stern wants to receive artificially administered nutrition and hydration. As with any other treatment, this is something that a patient (or the patient's surrogate) has a right to accept or refuse. It's necessary to obtain informed consent for the tube feedings. Ideally, however, the decision about tube feedings should be discussed within the context of a broader conversation about the overall goals of care. In this case, you should begin the discussion by asking Mr. Stern about his goals for care and whether or not he would like to receive this life–sustaining treatment.

D. Explore with Mr. Stern his goals of care and discuss whether or not artificially administered nutrition and hydration seem right for him.

Good choice. You didn't just assume that Mr. Stern wants to receive artificially administered nutrition and hydration. As with any other treatment, this is something that a patient (or the patient's surrogate) has a right to accept or refuse. It's necessary to obtain informed consent for the tube feedings. You also recognized that the decision about tube feedings should be discussed within the context of a broader conversation about the overall goals of care.

The bottom line: **Give the patient or surrogate the opportunity to accept or refuse all life–sustaining treatments, including artificially administered nutrition and hydration, which are consistent with desired and achievable outcomes and goals.**

Case Study 6

The correct answer is: D. Discuss pain management options with Ms. Sheppard and manage her pain in accordance with her wishes.

A. Change Ms. Sheppard's sheets only if necessary.

This isn't the best option. This may be an appropriate component of a comprehensive pain management plan for a dying patient, since burdensome treatments should only be considered if they help achieve the patient's goals. However, the team managing Ms. Sheppard's care needs to do more. It's a good idea to review the patient's orders and modify routine procedures that may cause the patient pain. It's also a good idea to treat pain proactively, and administer extra doses as needed. Appropriate use of opioids to relieve dyspnea has not been shown to hasten death. And even those treatments that may cause side effects or hasten death should be considered, if they are consistent with the patient's goals of care and the patient agrees with the plan. In this case, the team should begin by discussing pain management goals with Ms. Sheppard and then manage her pain in accordance with her wishes.

B. Give an extra dose of morphine before each bed change.

This isn't the best option. This may be an appropriate component of a comprehensive pain management plan for a dying patient, but the team managing Ms. Sheppard's care needs to do more. It's a good idea to review the patient's orders and modify routine procedures that may cause the patient pain. It's also a good idea to treat pain proactively, and administer extra doses as needed. Appropriate use of opioids to relieve dyspnea has not been shown to hasten death. And even those treatments that may cause side effects or hasten death should be considered, if they are consistent with the patient's goals of care and the patient agrees with the plan. In this case, the team should begin by discussing pain management goals with Ms. Sheppard and then manage her pain in accordance with her wishes.

C. Increase the dose of morphine until Ms. Sheppard no longer experiences any pain.

This isn't the best option. This may be an appropriate component of a comprehensive pain management plan for a dying patient, but the team managing Ms. Sheppard's care needs to do more. It's a good idea to review the patient's orders and modify routine procedures that may cause the patient pain. It's also a good idea to treat pain proactively, and administer extra doses as needed. Appropriate use of opioids to relieve dyspnea has not been shown to hasten death. And even those treatments that may cause side effects or hasten death should be considered, if they are consistent with the patient's goals of care and the patient agrees with the plan. In this case, the team should begin by discussing pain management goals with Ms. Sheppard and then manage her pain in accordance with her wishes.

D. Discuss pain management options with Ms. Sheppard and manage her pain in accordance with her wishes.

You're right. The team should begin by discussing pain management goals with Ms. Sheppard, and then manage her pain in accordance with her wishes. All of the other options may be appropriate components of a comprehensive pain management plan for a dying patient. It's a good idea to review the patient's orders and modify routine procedures that may cause the patient pain. It's also a good idea to treat pain proactively, and administer extra doses as needed. Appropriate use of opioids to relieve dyspnea has not been shown to hasten death. And even those treatments that may cause side effects or hasten death should be considered, if they are consistent with the patient's goals of care and the patient agrees with the plan.

The bottom line: **Provided they are consistent with the patient's goals of care, comfort measures and pain management should always be a priority, even if they may shorten life.**

Case Study 7

The correct answer is: D. Go see him and discuss the options.

A. Order 5–10 mg of IV morphine as needed for shortness of breath, and call his family.

This isn't the best option. Good instinct to address Mr. Allen's comfort, but first you must consider his goals of care. The fact that he has a DNR order and a history of serious illnesses does not necessarily mean that he wants comfort care only. You need additional information about his wishes. Mr. Allen's advance directive contains important guidance but since he still has decision-making capacity you should speak to him directly about his current condition and his options and make treatment recommendations that are consistent with his goals of care.

B. Call respiratory therapy STAT, and arrange transport to the ICU.

This isn't the best option. The fact that Mr. Allen has a DNR order and a history of serious illnesses does not necessarily mean that he wants comfort care only. However, it does provide important evidence about his goals of care. Before you act, you need additional information about his wishes. Mr. Allen's advance directive contains important guidance but since he still has decision-making capacity you should speak to him directly about his current condition and his options and make treatment recommendations that are consistent with his goals of care.

C. Send a respiratory therapist and a nurse to his bedside while you check his advance directive.

This isn't the best option. The fact that Mr. Allen has a DNR order and a history of serious illnesses does not necessarily mean that he wants comfort care only. However, it does provide important evidence about his goals of care. Before you act, you need additional information about his wishes. Mr. Allen's advance directive contains important guidance but since he still has decision-making capacity you should speak to him directly about his current condition and his options and make treatment recommendations that are consistent with his goals of care.

D. Go see him and discuss the options.

Good choice. The fact that Mr. Allen has a DNR order and a history of serious illnesses does not necessarily mean that he wants comfort care only. However, it does provide important evidence about his goals of care. Mr. Allen's advance directive contains important guidance but since he still has decision-making capacity you should speak to him directly about his current condition and his options and make treatment recommendations that are consistent with his goals of care.

The bottom line: **Unless other treatment limitations have been agreed on, treat patients with DNR orders as you would other patients except if they experience cardiopulmonary arrest.**

Case Study 8

The correct answer is: D. Determine whether he meets the eligibility criteria for hospice care.

A. Tell her that since his prognosis cannot be predicted with certainty, he is not a candidate for hospice.

This isn't the best option. Hospice is a covered benefit for all enrolled Veterans, on par with all other medical services included in the Medical Benefits Package. Therefore, all Veterans who meet the clinical criteria for hospice must be offered needed hospice and palliative care services, regardless of whether these services are needed in an inpatient setting or in the home. A patient is considered eligible for hospice if he/she: (1) is diagnosed with a life-limiting illness, (2) has treatment goals focused on comfort rather than cure, (3) has a life expectancy deemed by a VA physician to be six months or less if the disease runs its normal course, and (4) accepts hospice care. If the patient is not eligible for hospice care, many palliative care services can be provided through a different mechanism.

B. Offer to transfer him to an inpatient hospice bed when one becomes available.

This isn't the best option. Hospice is a covered benefit for all enrolled Veterans, on par with all other medical services included in the Medical Benefits Package. Therefore, all Veterans who meet the clinical criteria for hospice must be offered needed hospice and palliative care services, regardless of whether these services are needed in an inpatient setting or in the home. A patient is considered eligible for hospice if he/she: (1) is diagnosed with a life-limiting illness, (2) has treatment goals focused on comfort rather than cure, (3) has a life expectancy deemed by a VA physician to be six months or less if the disease runs its normal course, and (4) accepts hospice care. If the patient is not eligible for hospice care, many palliative care services can be provided through a different mechanism.

C. Offer to arrange home care with a hospice provider in the community.

This isn't the best option. Your willingness to arrange community-based hospice care demonstrates your commitment to Mr. Fiebach and his family. However, since he may be eligible for an inpatient hospice bed you should explore all options first. Hospice is a covered benefit for all enrolled Veterans, on par with all other medical services included in the Medical Benefits Package. Therefore, all Veterans who meet the clinical criteria for hospice must be offered needed hospice and palliative care services, regardless of whether these services are needed in an inpatient setting or in the home. A patient is considered eligible for

hospice if he/she: (1) is diagnosed with a life-limiting illness, (2) has treatment goals focused on comfort rather than cure, (3) has a life expectancy deemed by a VA physician to be six months or less if the disease runs its normal course, and (4) accepts hospice care. If the patient is not eligible for hospice care, many palliative care services can be provided through a different mechanism.

D. Determine whether he meets the eligibility criteria for hospice care.

Good choice. Hospice is a covered benefit for all enrolled Veterans, on par with all other medical services included in the Medical Benefits Package. Therefore, all Veterans who meet the clinical criteria for hospice must be offered needed hospice and palliative care services, regardless of whether these services are needed in an inpatient setting or in the home. A patient is considered eligible for hospice if he/she: (1) is diagnosed with a life-limiting illness, (2) has treatment goals focused on comfort rather than cure, (3) has a life expectancy deemed by a VA physician to be six months or less if the disease runs its normal course, and (4) accepts hospice care. If the patient is not eligible for hospice care, many palliative care services can be provided through a different mechanism.

The bottom line: **Hospice is a philosophy and approach to care, not a place.**

Case Study 9

The correct answer is: C. Knock on the door, pause a moment, then enter as a team, as you would with any other patient.

A. Don't burden him with routine visits; move on to the next patient.

This isn't the best option. Ideally, the clinician-patient relationship is a longitudinal, caring partnership that begins in health and continues through death. Clinicians need to be able to reassure patients that they will be there to relieve the patient's pain and suffering, rather than leaving them to face death alone. While many clinicians feel uncomfortable visiting dying patients, it is important to resist the temptation to avoid them; you should spend at least as much time with those who are dying as those who are expected to live. Patients should never hear "there's nothing more we can do." Instead, the message should be "You can count on us to help you." As an expression of concern for Mr. Shield's well-being, the team should knock on his door, and then enter.

B. Assign one person from the team to come back and visit Mr. Shield later.

This isn't the best option. Ideally, the clinician-patient relationship is a longitudinal, caring partnership that begins in health and continues through death. Clinicians need to be able to reassure patients that they will be there to relieve the patient's pain and suffering, rather than leaving them to face death alone. While many clinicians feel uncomfortable visiting dying patients, it is important to resist the temptation to avoid them; you should spend at least as much time with those who are dying as those who are expected to live. Patients should never hear "there's nothing more we can do." Instead, the message

should be "You can count on us to help you." The team should knock on Mr. Shields's door, and then enter.

C. Knock on the door, pause a moment, then enter as a team, as you would with any other patient.

You're right. Ideally, the clinician–patient relationship is a longitudinal, caring partnership that begins in health and continues through death. Clinicians need to be able to reassure patients that they will be there to relieve the patient's pain and suffering, rather than leaving them to face death alone. While many clinicians feel uncomfortable visiting dying patients, it is important to resist the temptation to avoid them; you should spend at least as much time with those who are dying as those who are expected to live. Patients should never hear "there's nothing more we can do." Instead, the message should be "You can count on us to help you."

D. Check with his primary nurse to make sure his symptoms are adequately controlled.

This isn't the best option. Ideally, the clinician–patient relationship is a longitudinal, caring partnership that begins in health and continues through death. Clinicians need to be able to reassure patients that they will be there to relieve the patient's pain and suffering, rather than leaving them to face death alone. While many clinicians feel uncomfortable visiting dying patients, it is important to resist the temptation to avoid them; you should spend at least as much time with those who are dying as those who are expected to live. Patients should never hear "there's nothing more we can do." Instead, the message should be "You can count on us to help you." The team should knock on Mr. Shields's door, and then enter.

The bottom line: **Resist the temptation to avoid patients who are dying.**

Case Study 10

The correct answer is: C. Seek an ethics consultation.

A. Withdraw the feeding tube on the basis of the advance directive despite Mr. Rubin's objections.

This isn't the best option. For many ethics questions, there is a clear answer in terms of the right thing to do. But in other instances, law, policy, and ethics may give conflicting information that may not resolve the question. In this case, your ethical obligation to honor Mrs. Rubin's wishes as expressed in her advance directive conflicts with her surrogate's authority to make decisions on her behalf. In such situations of uncertainty or conflict regarding shared decision making, the best option is to seek an ethics consultation.

B. Continue to give Mrs. Rubin artificial nutrition and hydration through the feeding tube.

This isn't the best option. For many ethics questions, there is a clear answer in terms of the right thing to do. But in other instances, law, policy, and ethics may give conflicting information that may not resolve the question. In this case, your ethical obligation to honor Mrs. Rubin's wishes as expressed in her advance directive conflicts with her surrogate's authority to make decisions on her behalf. In such situations of uncertainty or conflict regarding shared decision making, the best option is to seek an ethics consultation.

C. Seek an ethics consultation.

You're right. For many ethics questions, there is a clear answer in terms of the right thing to do. But in other instances, law, policy, and ethics may give conflicting information that may not resolve the question. In this case, your ethical obligation to honor Mrs. Rubin's wishes as expressed in her advance directive conflicts with her surrogate's authority to make decisions on her behalf. In such situations of uncertainty or conflict regarding shared decision making, the best option is to seek an ethics consultation.

D. Seek a court order to withdraw treatment.

This isn't the best option. For many ethics questions, there is a clear answer in terms of the right thing to do. But in other instances, law, policy, and ethics may give conflicting information that may not resolve the question. In this case, your ethical obligation to honor Mrs. Rubin's wishes as expressed in her advance directive conflicts with her surrogate's authority to make decisions on her behalf. In such situations of uncertainty or conflict regarding shared decision making, the best option is to seek an ethics consultation. If an ethics consultation does not resolve the concern, court intervention may be appropriate.

The bottom line: **When you cannot resolve situations of uncertainty or conflict regarding end-of-life care, seek an ethics consultation.**